

PROMISING PRACTICES IN HOME AND COMMUNITY-BASED SERVICES

Utah -- Family-Directed Support Network for Families of People with Disabilities

Issue: Support, information, and resources for family caregivers

Summary

Utah's network of family-directed councils provides an opportunity for families of individuals with disabilities to share support, education, and resource information. The statewide network of organizations is available to all families of individuals with disabilities, including families who do not receive publicly funded services. A formal evaluation of the councils' effectiveness has not been conducted, but state staff report council participants benefit from the increased support, awareness, and empowerment.

Introduction

In the past, families of people with disabilities in Utah often did not know how to seek publicly and privately funded services. Most supports available to families were parent training centers and support groups that catered to individuals with particular disabilities. Several families in Utah formed the State Family Council, a nonprofit organization that enables all families of people with disabilities to support one another, share ideas, and learn about available services. The State of Utah and the State Family Council used funds from a Robert Wood Johnson Foundation Self-Determination Grant to create a network of local family councils throughout the state.

This report briefly describes the councils' activities and resources, the expansion of local councils, and state assistance to these councils. The State Family Council's Web site and interviews with Utah and State Family Council representatives provided information for this report.

Background

Utah increased the availability of family councils after a January 2000 report written by families detailed what worked and did not work in Utah's family support services. Prior to the report, family councils existed within a few communities.

The previous councils received informal support from Utah's Division of Services for People with Disabilities (DSPD), such as meeting space and secretarial support, but no financial support.

Intervention

During the Self-Determination Grant, DSPD and the State Family Council created 35 local councils that serve the entire state. The State Family Council also created four regional councils consisting of selected local council officers. The State Family Council consists of regional council representatives. All family council members volunteer their work and time, except for an executive director and associate director of the State Family Council.

Families learn about the family councils in many ways including state and local council web sites, newsletters, brochures, conferences, and word of mouth from providers, schools, and other families. Originally, the councils only served families of children with disabilities. They expanded their services to all families of people with disabilities, regardless of age or diagnosis.

Family council members often help one another identify available services and funds, decipher technical language, complete paperwork, locate employment and equipment, and identify other

Families of people with disabilities often do not know how to obtain services.

Family Council members help one another identify services and provide other types of assistance.

tools necessary to advocate for their family members. The councils also provide input to DSPD, the Governors Council for People with Disabilities, and the state legislature regarding services and policies that effect people with disabilities.

In addition, local councils have initiated projects to improve the quality of life of people with disabilities. Projects vary according to the needs of the local community. Examples include creating a public awareness campaign for elementary schools, providing baby blankets with support information to mothers of newborn babies with disabilities, developing recreational programs, mentoring new parents, and assessing the quality of provider services.

Implementation

DSPD and the State Family Council used funds from a Self-Determination Grant from the Robert Wood Johnson Foundation to establish dozens of new local councils and to increase awareness of the network of family councils. The initiative began in 2000 and took approximately one year. Families established many local councils in the initiative's first four months because demand for the councils was high.

The first step to creating a new local council was an informational dinner. The State Family Council planned a dinner in a community after one or more families requested to establish a council. When planning the informational dinner, the state chair invited families of people with disabilities identified by the Family Council and by DSPD. These meetings were usually very successful in raising interest for a local council, and officers were often elected by the end of the meeting.

For new councils, the State Family Council provided training and materials to guide new officers on implementing and managing a council. The training and materials covered topics including running elections, creating

budgets, and working with difficult people. State Family Council officers identified these topics for training through previous council experience and through general knowledge of organization management.

When a local council was established, its first project was to identify the community needs related to people with disabilities. Councils also provide advocacy and assistance to people with disabilities, and provide orientation for new recipients of DSPD services.

The cost to implement and manage each of the councils depends on the number of participants and the population represented within the council. Costs incurred included transportation, guest speakers, training, refreshments, telephone calls, printing, marketing, and space for meetings.

One challenge for family councils was communication and travel in rural areas. Rural councils covered large geographic areas to enable the network of councils to serve the entire state. Council members used the Internet and email to improve communication and move projects forward with fewer in-person meetings.

From 2000 through 2004, DSPD supported family councils through a contract with the State Family Council. This contract funded the state chair's part-time position; secretarial support and accounting services for the State Family Council; and small operating budgets for the local and regional councils (\$150 to \$200 per year). The contract also paid travel expenses and respite care for families attending council meetings, including those who did not typically receive publicly funded services. The contract was for approximately \$60,000 each year. DSPD also assigned one case manager to support each local council. The case manager worked 10 – 15 hours per month to send out mailings, photocopy resources, make telephone calls, and make transportation available. DSPD estimated the value of its in-kind support was \$30,000 per year.

In July 2004, DSPD allowed other organizations to bid on a new contract to support the councils. DSPD awarded a three-year, \$95,000 per year

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contract to the Governor's Council for People with Disabilities, Utah's state council on developmental disabilities funded in part by the U.S. Department of Health and Human Services, Administration on Developmental Disabilities. This contract includes additional funds to replace the in-kind support that DSPD had provided.

The State Family Council allowed the Governor's Council to continue to work with the network of family councils already established. Under the new contract, three part-time Governor's Council staff provide training assistance to the family councils.

To replace the in-kind support, local councils have a larger budget (\$750) to pay for brochures, mailings to families, and respite for council attendees. While local councils have a larger budget, they have had more difficulty using these funds. State procurement rules prevent the Governor's Council from giving grants to local councils, as the State Family Council did. Instead, families must pay out-of-pocket for speaker expenses, mailing expenses, transportation, or other items, and then request reimbursement from the Governor's Council. This requirement has reportedly prevented some local councils from continuing or initiating activities. DSPD and the Governor's Council are

examining how to streamline the process for local councils.

Impact

An estimated 50 to 65 parents are in leadership roles within the Utah Family Councils, such as leading local councils or planning statewide events. No formal analysis of the Council's effectiveness has been performed. Quarterly reports document the councils' projects and accomplishments. Informal indicators of the councils' effectiveness include unsolicited statements of satisfaction and the strong communication network that has been established among families.

Contact Information

For more information about the establishment of Utah's network of family councils, please contact Pheobe Blackham, State Family Council Chair at (877) 352-2221 or Pmbalp@aol.com. For more information about current family council operations, please contact Claire Mantonya of Utah's Governor's Council for People with Disabilities at (801) 533-3965 or clairemantonya@utah.gov. Online information about Utah's family councils is available at <http://www.gcpd.org> and <http://www.statefamilycouncil.org>.

Discussion Questions:

In addition to the state, what other organizations may provide support for the Family Council?

How can the Family Council's effectiveness be measured?

The original report was written by Erin Barrett, L.S.W. Medstat revised this report, one of a series of reports for the U.S. Centers for Medicare & Medicaid Services (CMS) highlighting promising practices in home and community-based services. The entire series is available online at CMS' Web site, <http://www.cms.hhs.gov/promisingpractices>. This report is intended to share information about different approaches to offering home and community-based services. This report is not an endorsement of any practice.